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ABSTRACT

The report describes the Kona Infant and Child Development Program for developmentally delayed/disabled/high risk children in the rural areas of West Hawaii. The first chapter of the report presents geographic and demographic background information and reviews the services prior to 1978 when the Kona program began. Chapter 2 describes the three major processes of collaboration, cooperation, and incorporation which brought together the Departments of Health and Education, to provide comprehensive services. Chapter 3 evaluates program efforts in terms of 13 major objectives (such as development of individualized education programs, and promotion of parental involvement) as well as lost benefit figures. Chapter 4 discusses program aspects and the underlying reasons for their development. The final chapter considers the future of the project and briefly examines replication factors. (CL)

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KONA CHILD DEVELOPMENT PROGRAM

FINAL REPORT

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STATE OF HAWAII
DEPARTMENT OF HEALTH
KONA CHILD DEVELOPMENT PROGRAM
P.O. BOX 228
KEALAKEKUA, HAWAII 96750

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KONA CHILD DEVELOPMENT PROGRAM

Prepared by:

Shirley A. Mayfield, M.Ed.

September, 1984

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INTRODUCTION

The Kona Child Development Program is located on the campus of Konawaena School in the town of Kealakekua on the Kona Coast of the island of Hawaii. For the past five years the program has been a federally funded collaborative project of the Hawaii State Departments of Health and Education.

The purpose of this program is to provide an integrated continuum of health and educational services to developmentally disabled children, from birth through age five years, who live in the rural areas of west Hawaii. The grant originally proposed that the program should provide a model which might be used as a basis for acquiring state support for these services in rural Hawaii. The federal grant ended in September 1983 and a written agreement to continue these services through the Kona Child Development Program was drafted and signed by the State Director of Health and the State Superintendent of Education.

The first chapter of this report provides some geographic and demographic background relating to the Kona area and the history of services to handicapped children prior to 1978 when the model Kona Child Development Program came into being. The second chapter describes the three major processes of collaboration, cooperation and incorporation, which were necessary to bring together the services of the two state agencies, the Departments of Health and Education, to provide comprehensive services to these children.

Chapter Three evaluates the program's efforts from a number of perspectives including the project's major objectives and how they were accomplished. Cost benefit is discussed as well as parents' views on the program as revealed in two case studies.

Chapter Four attempts to draw out and analyze those elements that have made the program special enough to be declared a "Project of National Significance" by the National Review Project at the Frank Porter Graham Child Development Center, University of North Carolina, Chapel Hill.

Chapter Five considers future needs, problems and plans for service to handicapped children in Kona and neighboring rural areas.

This report is intended for all interested persons who work with programs for young handicapped children. It is hoped it will provide some insights and information that may be useful.

CHAPTER ONE

BACKGROUND

The North and South Kona Districts on the western side of the island of Hawaii cover an area of approximately 858 square miles. The larger Kona area is generally rural, with much of the land devoted to various agricultural uses including the growing of coffee and macadamia nuts. The terrain is mountainous with precipitous cliffs rising from resort beach areas to mountainside towns and villages which are connected by a network of state highways and county roads. Transportation is primarily by privately owned motor vehicles with limited bus service available.

Population

In 1970, the population of the North and South Kona areas was 8,834. This increased to 19,662 in 1980 and is now estimated at approximately 22,500. Nine percent of the population is made up of children under age six. As is true throughout the state, the population consists of a mixture of ethnic backgrounds, including Japanese, Caucasian, Hawaiian, Chinese, and Filipino.

History of Health Services

Because of the relatively sparse population and rural nature of Kona prior to and around 1978, few doctors or other health care professionals were attracted to the area. Health services for young children with developmental disabilities were available on an itinerant basis from the State Department of Health. Patients with conditions serious enough to threaten life or requiring surgical intervention or special treatments were usually taken by air to Honolulu for hospitalization and treatment.

Before 1974, some diagnostic services were provided by itinerant Department of Health therapists and physicians. There was no intervention program available to families of infants and young children identified as developmentally disabled. Services to developmentally disabled children were clearly divided by age groups with the Department of Health assuming responsibility for children under age five and the Department of Education serving those age five and over.

In 1974, the Department of Health established a program for a small group of developmentally disabled infants and young children and their families under the direction of the current occupational therapist/coordinator of the Kona Child Development Program. When the program grew too large for the coordinator's home where it had been meeting, it was relocated in a vacant ward at Kona Hospital where it continued to operate for two and one-half years.

In 1975, the passage of Public Law 94-142 allowed funding for the education of handicapped children below the age of five years. The Hawaii Department of Education elected to provide services for developmentally disabled children from the age of three years. Special education teachers and educational assistants were already assigned to each school. Each district had a diagnostic-prescriptive team who evaluated and certified children and made programming recommendations to teachers.

In response to the passage of Public Law 94-142 and its implied overlap of responsibility between health and education, the federal government made funds available to six states for innovative programs that would demonstrate

effective collaborative effort between health and education agencies in providing a full range of services to handicapped children. It was apparent to both the Hawaii Departments of Health and Education that only through collaboration between the two would it be possible to provide the spectrum of services required to meet the full range of needs of all young developmentally disabled children and their families in this rural and isolated area. Hence, in October 1978, the staffs of the Kona Child Development Program and the Department of Education preschool staff combined to form the model Kona Child Development Program. With funding and contributions in kind from the Department of Health, Department of Education, Title V and Title XX, the project moved from Kona Hospital to its present location on the campus of Konawaena School. The project is housed in two former teachers' cottages, a heritage of its rural setting, to allow a transition between home and school.

CHAPTER TWO

SERVICE MODEL

The conjoint efforts of the two state agencies, the Department of Health and the Department of Education, guide the implementation of a full range of services from public education and screening to diagnostic services, appropriate program placement, ongoing interdisciplinary assessments, appropriate interventions including training/treatment, psychological services, skills teaching to parents and follow-up services. The collaboration of the Departments of Health and Education has also made it possible to include children from birth to seven years, although the Project concentrates mainly on children 0-5 years of age.

Three processes -- collaboration, cooperation, and incorporation--facilitated the provision of comprehensive services to the developmentally disabled/delayed children and their families in the program. Collaboration in the Kona Child Development Program refers to the agreement between two government agencies, the State Departments of Health and Education, to jointly serve young handicapped children in the Kona Coast area. Cooperation is evident in the working together of private and public providers which complements and expands services offered by the two major agencies. Incorporation is the utilization of identification, diagnostic and evaluation functions of both major agencies.

The collaboration between the Department of Health and Department of Education to operate a program for infants and preschool handicapped children has become a natural and integral part of the greater service community. The essence of this model is the provision of services through the network of comprehensive services described below.

Working Together: The Network of Comprehensive Services:

A. The Center

The Department of Health's Kona Child Development Program and the Department of Education's Konawaena School are the nuclei of this health-education network. The Department of Education provides the facilities for the program which include two renovated teachers' cottages. A spacious outdoor playground is available and all utilities are provided by the Department of Education.

B. Interdisciplinary Team - Program Staff:

Occupational Therapist: The occupational therapist serves the dual roles of program coordinator and therapist. As occupational therapist, she is responsible for evaluation, treatment, and consultation. Treatment includes facilitation of developmental skills in the perceptual, fine motor, and self-care areas. Formal tests such as the Southern California Sensory Integration Tests are used with some children. She designs, constructs, and adapts appropriate equipment that will enhance the child's total development.

Medical Social Worker: The social worker provides social casework services individually and in groups, serves as a case manager to help coordinate all needed services for the family, assumes primary responsibility for screening and case finding, and coordinates the diagnostic clinics.

Para-Medical Assistant: The para-medical assistant assists team members in promoting each child's individual developmental plan. She demonstrates activities to parents that are designed to foster appropriate behavior of their child.

Homemaker: The homemaker helps maintain developmentally disabled children in their own homes, an important feature in this rural area where there still are no resources for respite care or foster placement. The homemaker has a variety of responsibilities in the Kona Program, but her primary tasks are to provide supportive services to families experiencing stressful situations, to provide

personal care and training activities of daily living to the developmentally delayed chidlren and to assist the family with training activities.

Special Education Teachers: The special educators evaluate the preschool children to determine their pre-academic and developmental skills and develop Individualized Educational Programs. They provide opportunities to maximize the child's skills through a variety of teaching-learning situations. They create materials for each child's curriculum. They coordinate the input from the occupational therapist, physical therapist, speech therapist, and psychologist to maintain an integrated program for each child as stated in the child's Individualized Educational Program. The teachers are also responsible for the training and supervision of the educational assistants.

Speech and Hearing Therapist: The speech therapist evaluates the hearing and speech and language development of each child. Her 6 hours of service a week includes direct therapy, programming, evaluation and consultation.

Educational Assistants: A vast majority of the workload for the educational assistants is in individual or small group instruction. They monitor lunch, free play and nap time. The aides also do some non-teaching activities including maintenance of supplies, clerical work, and classroom paperwork.

C. Interdisciplinary Team: Fee-for-Service Personnel:

Pediatrician: The pediatrician provides consultation regarding medical concerns of the children and conducts in-service training as needed.

Psychologist: Once a month the psychologist does evaluations and provides consultations. She also provides support to parent groups and conducts workshops for staff and parents.

Physical Therapist: The physical therapist does gross motor evaluations to include general coordination, balance, agility, and strength. She is responsible for incorporating specific physical therapy findings into the child's treatment program which is implemented by the therapist, parents and staff members.

D. Interdisciplinary Team: Department of Education Support Service

Speech Therapist: Twice weekly, the speech therapist sees children in the preschool program. Her services include therapy, programming, evaluation and consultation.

Occupational Therapist: Once a week, the occupational therapist formally and informally does evaluations and plans treatment programs to facilitate developmental skills in the perceptual, fine motor, and self-help areas. She also sees children on an individual and group basis for therapy and provides consultation to the staff. She is also responsible for selecting, designing, constructing or adapting appropriate equipment that will meet the needs of individual children.

Physical Therapist: Twice weekly, the physical therapist works with children in the preschool program providing gross motor evaluations and therapy, and incorporating specific physical therapy recommendations for staff and parents to implement.

E. Services that are Incorporated or Partly Incorporated

1. The Department of Education Diagnostic Team consists of four members--a psychological examiner, an educational therapist, a social worker and a speech-language specialist. The team provides a comprehensive diagnostic evaluation for any child three years or older to determine if the student is eligible to receive special services in a special education program.

2. The Department of Health continues to provide screening, diagnostic evaluation, ongoing assessment and consultative program services through the Preschool Developmental Screening Team, Child Development Clinic, and School Health Services.

   Screening activities became a part of the Kona Project when the Preschool Developmental Screening Team of the Maternal and Child Health Branch of the Family Health Services Division of the Department of Health provided orientation and training to the Kona Child Development Program staff and to the preschools in the area; the team also provides consultation, materials and supplies, and occasional financial assistance when team services are involved. In January, 1983, a part-time screener was hired through funding from Maternal and Child Health Branch. Through the efforts of the Kona Child Development Program's social worker, six of the eight preschools in Kona expressed interest in participating in a screening program. This screening allows the Kona team to 1) identify children who need to be placed in the Child Development Program, or 2) provide consultation for prescriptive programming to school personnel when the child can remain in a regular pre-school, or 3) assure that the child/family has the opportunity to receive needed services. Parental consent for screening is obtained and the Department of Health Developmental Checklist and Preschool Behavior Questionnaire (PBQ) and Developmental Indicators for the Assessment of Learning (DIAL) screening are administered. The Department's Child Development Clinic provides comprehensive diagnostic services to eligible children suspected of developmental delays/disabilities, including those who have failed screening. Components of the

interdisciplinary team include the social worker, psychologist, physician, physical, occupational and speech therapists, and nutritionist. Vision and hearing screening are provided by the School Health Services Branch and the Assistance League which employs a private audiologist.

3. Department of Social Services and Housing - Many families known to the infant program require financial and/or medical assistance. Services to children known to Child Protective Services need to be coordinated with the Department of Social Services and Housing.

The Infant Program: 0 to 18 Months, (DOH)

The Infant Program provides individualized instruction in motor, social, language, and cognitive development for children from birth to 18 months of age. The parents and program staff complete the Early-LAP (Learning Accomplishment Profile) on each child which is used as an assessment tool and guide for setting program objectives. The results are discussed with parents so they have a clearer understanding of the child's level of functioning. Specific activities are prescribed for each child to enhance functioning.

Parents are a crucial aspect of this program. The focus of parent training is to provide the bases from which parents will increase their knowledge and skills in child care. The staff provides parents with the knowledge and the ability to implement developmental activities with their child so training is continued in the home. Each parent and child comes to the Center for weekly one hour sessions.

The Toddler Program: 18 months to 3 years, (DOH)

The Toddler Group includes the children from 18 months to 3 years who are pretested on the Early-LAP (Learning Accomplishment Profile). The psychologist also shares results from Bayley Infant Development Scale, the Stanford Binet, the Kaufman Assessment Battery for Children and other clinical tests with the staff. The deficit skills are prioritized by the parents and program staff and the child is individually programmed in the areas of gross motor, fine motor, language, self-help, cognitive, and social skills. The toddler group attends the Center 3 to 4 mornings a week.

Early identification, assessment and intervention in the birth to 3 year old group has made significant differences in their development and adjustment, enabling them to move smoothly into the preschool group. Using the Early-LAP with this group has made it easy to transfer progress and objectives into the preschool curriculum where the version of the LAP appropriate for this age group is used.

Preschool Program: Department of Education Certified Children: 3 to 7 Years, (DOE)

The Preschool Program serves children ages 3 to 7 years who have special education needs and who have been certified under the Department of Education's criteria of handicapping conditions. While there is a wide range of intellectual, developmental, social and emotional skills represented by the children in this age range, each child is grouped according to his or her own abilities with others who function similarly. Educational and developmental needs are determined by assessments which provide each child's level of functioning in fine motor, gross motor, language, social, self-help, cognitive development, visual perception, and auditory perception. Primary tools for assessment are the Early-LAP and the LAP which provide the necessary data to ensure a smooth transition from the Toddler Program into the Preschool Program.

The preschool group consists of four components - the preschool group, the self-contained class, kindergarten transition class, and first grade transition class. The design of the program provides individualized and group educational and developmental activities to all four groups. The children in the kindergarten transition class receive intensive readiness activities in a carefully structured learning environment. The first grade group uses the curriculum of the regular classroom in language arts and mathematics, but the teacher presents the material in a format that will allow each child to grasp the concepts of these content areas. An important aspect of the preschool program is the development of positive attitudes toward learning, as well as the classroom behaviors that will allow the child to function successfully in the regular education classes. By having the children divided into small groups for teacher-directed learning, many educational and developmental goals have been achieved and well documented.

During the child's last year at the Kona Child Development Program, she/he is introduced to the larger classes and requirements of the regular classroom routines. This is accomplished by first integrating the child into the afternoon program in special education (10-12 children) at Konawaena Elementary, and then finally into the regular classroom (26-30 children). This allows the children to "try their wings" in a controlled way as well as to gradually wean them from their dependency on the program.

The Home Program

The Kona Child Development Program operates on the belief that every child is a unique individual. Because parents and siblings usually are the child's most important and most available resources, the needs of the family must also be served. In some cases, family members' needs are greater than the immediate needs of their handicapped child.

Because the Kona area is sparsely settled over a large geographic area, services are not often accessible or even available to many families. The Kona Child Development Program provides for these isolated families through the services of a social worker and a homemaker, vital roles in a program that works with many high risk families with serious psychological problems and concerns. The objective behind the provision of related services is to

improve and strengthen the family's ability to cope, thus enhancing family stability and harmony. A home visit by the social worker is the family's first contact with the Program. The purpose of this visit is to make the family aware of the services provided by our program and to delineate the involvement that is expected of them. The homemaker is also utilized in providing services to children who are unable to come into the program. She has the unique advantage of teaching feeding and dressing skills in the home within the child's established routine. These outreach services are provided under the direction of the professional staff.

CHAPTER THREE

EVALUATION

The Kona Child Development Program received recognition for successfully achieving its goal of providing an integrated continuum of health and educational services to developmentally disabled children from birth through age seven years who live in rural Hawaii. It was selected as one of seven outstanding demonstration projects by the National Review Project at the Frank Porter Graham Child Development Center, University of North Carolina, Chapel Hill. The National Review Project stated that the Kona Child Development Program "provides trans- or multi-disciplinary services and is linked with other services in the area to provide comprehensive services to developmentally disabled children." (A copy of the National Review Project Report is in the Appendix).

Implementation of the project's primary goal of "providing integrated services for infants and preschool handicapped children with special needs in West Hawaii," has been described earlier. The major objectives subsumed under that goal will be addressed.

Objectives 1 and 2 -- Department of Education and Department of Health personnel and parents will complete an Individualized Education Program for all certified and non-certified and developmentally delayed children 3-5 years old.

Objectives 1 and 2 are ongoing objectives that are implemented as new children enter the program.

The staff formulates an Individualized Education Program (IEP) on each child based on the results of the Learning Accomplishment Profile (LAP) and holds an IEP conference with the parents. Each family receives short term objectives to work with their child when she/he is not at the center. A quarterly report is written on each child and a meeting is held with the parents to discuss the child's progress.

Objective 3 -- Department of Education and Department of Health personnel and parents will begin an Individualized Developmental Program for all handicapped and developmentally delayed children 0-3 years old.

Objective 3 is an ongoing objective that is implemented as new children enter the program. Using the Early-LAP as an assessment tool and guide for setting program objectives, the staff and parents formulate an Individualized Developmental Program and a conference is held on each infant and toddler age child. The family receives a weekly worksheet with developmental skills to work on at home.

Objective 4 -- A program will be implemented to provide liaison public relationships and community involvement with Kona community professionals and other Kona community service organizations.

An open house was held in November 1978 to welcome people to the new interagency program on Konawaena campus. It was well attended by various professionals and agency people in the community. Throughout the years, many community professionals have addressed the parents on topics such as speech and language stimulation, preventive dental care, disciplining your children, pediatric care and immunizations, the brain and its development, etc. In March 1980, the March of Dimes provided funds for a toy lending library which is completed and operational.

On April 7, 1981, an open house was held in celebration of the International Year of Disabled Persons. On April 11, 1981, a 30-minute slide presentation and discussion on the Kona Child Development Program was given at the Special Education Fair at Konawaena Elementary School. Participants from Kona Child Development Program included a Medical Social Worker and the Occupational Therapist/Coordinator. All of the special education teachers on the island of Hawaii attended the fair. A booth was set up displaying materials used at the program and a program brochure, which was completed in April, was available for interested teachers.

On April 18, 1981, Program Coordinator, Claire Oue, presented a talk titled, "Public Agencies Can Work Together," at the 32nd Annual Convention of the Association for Retarded Citizens.

Objective 5 -- A psycho-social diagnostic treatment plan will be outlined for each family in need of counseling and casework service.

While recognizing the importance of parent participation in the education and training of their handicapped children, the Kona Child Development Program also takes into consideration the fact that many of the parents enrolled in the program may have needs of their own which sometimes interfere with their ability to parent and to learn parenting skills. In addition to the stresses created by unemployment, inadequate income, marital disharmony, separation or divorce, family violence, (including spouse and child abuse,) isolation, and conflicting value systems created by cultural transitions in a culturally mixed society, parents must also cope with generalized stresses imposed by the growing pains of the Kona area. The psycho-social diagnostic treatment plan developed by the social worker attempts to address these and other concerns for each family and is continually reviewed and updated. The social worker may provide individual and group counseling, conduct parent groups, and refer families to other agencies.

Objective 6 -- The summer Department of Education and Department of Health program plan will be developed for implementation.

A summer program was initially developed in 1979 and each year a plan is developed and implemented for a summer session. The Department of Education and Department of Health are presently working on the plan for the summer of 1984; the program runs for six weeks from mid-June to July 31.

Objective 7 -- A system will be established to review the progress and performance of each child and plan appropriate program revision.

The staff meets bi-monthly to review the Individualized Educational Plan and IDP progress on each child. Objectives are continually updated and parent-staff conferences are held quarterly. A parent-staff conference is held annually for IEP review.

Objective 8 -- An outreach plan will be developed to approach and involve Kona physicians, nursery schools, appropriate agencies and persons for implementation.

Ongoing contact is maintained with the two pediatricians in the Kona area, the public health nurses, and Department of Social Services and Housing regarding referrals. Consultation is also available to health, education and social services providers; developmental screening and follow-up services for preschool age youngsters have become part of the program's functions.

Objective 9 -- A plan will be established to foster and improve parental involvement in the program and enhance parental skills in promoting development of their child.

In 1979, parent meetings were discontinued due in part to parents' work and home schedules. Plans to develop parent groups have resulted in utilization of community resources as well as program staff:

1. A number of parents attend a program sponsored by a Department of Health Mental Health Division grant to provide informational (e.g., on child development) and therapeutic (e.g., identification and dealing with feelings/stresses associated with having a handicapped child) services.

2. A parent training package is being developed which will include audio-visual materials as well as printed materials. Because of the range of disabilities, this package must include a variety of materials that will serve to orient parents of newly certified children.

3. Parent Effectiveness Training, which was formerly presented by the staff, is now available through community resources.

Objective 10 -- Publicity activities will be developed to disseminate information regarding the interagency project to the Kona community.

The Kona Child Development Program has received extensive coverage in West Hawaii Today, a local newspaper. A community service announcement appears weekly in this newspaper. A monthly program newsletter was initiated in October 1978, but was discontinued in September 1979, due to the increased costs of printing. Plans are now being made to resume the newsletter.

A new pamphlet titled, Kona Child Development Program describes the interagency program.

A slide show created in 1981 describing the project is now being updated.

Objective 11 -- A multidimensional format will be designed to foster the concepts of staff training, enrichment, development and continuing education in order to promote positive organizational growth of the project to extend its services to meet the unique needs of its developmentally disabled children.

Staff and team development continues to be a high priority. In-service training for staff (particularly educational assistants) on topics as behavioral management, handicapping conditions, positioning, child development is provided on a regular basis by primary program staff, pediatric consultant, psychologist, and Departments of Education and Health personnel. Staff is encouraged to attend seminars and workshops held sponsored by other agencies. Plans have been made to videotape each child and family to capture the developmental, behavioral, and interactional aspects; videotapes can then be used for historical and teaching purposes. In addition, the Kona Child Development Program resource library is being expanded as funds are available.

Objective 12 -- A plan for implementation of satellite programs for outlying communities, such as Milolii, Hookena, Pu'uanahulu, Waimea, Kohala, will be formulated.

Satellite programs are not a reality due to lack of staff and a vehicle to reach these rural communities. However, children in the outlying communities have received services by being brought into the primary center.

The Kona Child Development Program staff are acting as consultants to a Jobs Bill Project in the community of Waimea where an outreach aide is identifying children who need special services.

Objective 13 -- A recreation program especially suited to the children's needs will be developed.

Proposed swimming lessons at the YWCA were not implemented because transportation was unavailable.

Cost Benefit

With the current national/international financial crisis, and resultant lessening or unavailability of funds for human services in our country, cost benefit has become the measure by which service projects stand or fall. Basically, the program is a preventive one, an early intervention process designed to maximize development and facilitate adaptation of the high-risk developmentally disabled child's life and family. Certainly the human value evident in the alleviation of suffering, in maximizing or enhancing the child's and the family's life, is the program's reason for being.

The contribution the program has made to the quality of life for families and their children during the time the children were enrolled is reflected in the interviews with parents which are presented at the end of this chapter. Clinical observations tell us that most of the families have made very positive changes in their feelings about having a handicapped or delayed child. These changes have brought about improved interaction with the child and improved cooperation and assumption of shared responsibility with the program for their child's training and education. Without the support and

services offered to families by the program, a number of children may not have been able to remain in their homes and may have required institutionalization or perhaps even more intensive therapeutic services.

In terms of monetary costs, institutionalization costs the state approximately $30,000 per year per child. (This figure, from the State Commission on the Handicapped, is the average cost for institutionalization of an individual in the state home for handicapped children or in the state hospital.) In comparison, the Hawaii Department of Health Infant Development portion of the Kona Child Development Program costs approximately $1,348.00 per year per child for children 0 to 3 years of age. According to the figures from the Hawaii Department of Education, the cost of regular education is about $2,800.00 per year per child. Special education costs are $700 per year more per child per year. A student certified in kindergarten and remaining in special education for the next 13 years would cost the state $9,100.00 more than if that child had been able to remain in a regular educational setting throughout the school years. We cannot say what will happen to these children in the future, but at the present time they have demonstrated their ability to function in the regular classroom. If all or most are able to maintain the gains made during the preschool years, and to remain in the regular school placement throughout, the state could save as much as $182,000.

When measured against entry evaluations and medical/developmental prognoses, current school placement of children discharged from the Kona Child Development Program suggests that the program has been successful in its preventive efforts in that discharged children have required fewer special education services than would be expected, and no child, regardless of early prognosis, has required institutionalization or residential placement.

The number of children served by year in the Kona Child Development Program from October 1978 to September 1983 (unduplicated) is:

1978-79	--	35 children
1979-80	--	32 children
1980-81	--	43 children
1981-82	--	48 children
1982-83	--	42 children

The program has served children with many types of handicapping conditions, including mental retardation, cerebral palsy, arthrogryposis, learning impairments, learning disabilities, hearing impairments, blindness, prematurity and high risk infants, speech and language impairment, and emotional problems.

The status of the children served from October 1978 to September 1983 is as follows:

Mental Retardation	--	18 children
Learning Impaired	--	20 children
Developmental Delays	--	20 children
Visually Impaired	--	4 children
Blind	--	1 child
Hearing Impaired	--	1 child
Deaf	--	1 child
Deaf/Blind	--	1 child
Orthopedic (includes arthrogryposis, spina bifida, and cerebral palsy)	--	12 children
Speech Language Impairments	--	5 children
TOTAL		86 children

Note that 52% of the developmentally delayed and disabled children have been decertified (a child is decertified from special education classification according to a determination based on current assessment of a child's level of functioning) upon or within one year. To date, 20 of the children who have been diagnosed as blind/developmentally delayed/learning impaired and discharged from the program have been decertified at the time of discharge or within one year. In addition at least 8 other children who are or have been enrolled in the program were regarded as potential candidates for residential placement.

Case Study:

Interviews with parents of two of the children are included to illustrate fairly typical case profile and program course. According to early medical records, the prognosis for both these children was extremely poor, yet both are now successfully attending public school, with one child being mainstreamed on a part-time basis and the other decertified because he no longer meets the criteria necessary to receive services as a handicapped child. The success of these two children is representative of a fairly large percentage of children discharged from the program.

Child K.

K., the youngest of three brothers, was born September 8, 1977. He was nine weeks premature, a transverse presentation that necessitated a Caesarean section. K. weighed four pounds at birth. He had trouble breathing, required oxygen, and was placed in an incubator. He was cyanotic, required intubation, was jaundiced, a poor feeder with a weak sucking reflex who "cried all the time" and had seizures. During the two and one-half months he spent in the incubator, K. had several lung collapses, many seizures, wheezing, and upper respiratory infections for which he received antibiotics. His diagnosis was "profound neonatal asphyxia" and one physician reportedly suggested that the staff shouldn't "try too hard to save him."

Released from the hospital pediatric pulmonary center at three months, K. was back within months because of cardio-pulmonary arrest with upper respiratory infection and bronchial pulmonary dysplasia. He managed to respond to treatment and was again released to his parents.

At age seven months, K., unable to swallow and near drowning in his own secretions, was evaluated and enrolled in the Kona Child Development Program, where he was assessed and an intensive stimulation and training program was developed for him along with occupational and physical therapy. At age 14 months, the physician who did a neurological evaluation of K. suggested that he was probably mentally retarded as well as motorically slow.

The Kona program staff intensified their efforts, continuing to work with K. and his parents. Fifteen months later, at age 29 months, K. received a psychological evaluation from the State Department of Health Child Development Clinic and achieved an intellectual quotient of 89 on the Stanford Binet Intelligence Test. The examiner remarked that K. was "probably of at least average abilities" and that he seemed to be "going through a developmental spurt that has brought on some remarkable gains."

According to this report of April 1980:

> K. has made remarkable progress in the past two years in gross motor, speech and language development and cognitive abilities. Initial entry into KCDP showed his behavior to be very irritable and unhappy, he had separation difficulties from Mom and would spend the entire sessions at the program crying. Now K. is walking, talking, and participating with peers well and learning rapidly. He is totally toilet trained. The most marked improvement in K. emerged once he started walking at 22 months and was able to do things independently.
>
> Much of K.'s current progress can be attributed to his mother's tireless efforts and energies expended in bringing him faithfully to KCDP and the concurring medical services. Her cooperation with the staff and her relentlessly inquiring attitudes toward his medical treatment and educational progress have been admirable.

Mrs. D., K's mother, expressed the following in interviews:

> If it weren't for the Kona Child Development Program, I don't know what I would have done. Without the instruction, knowledge, and encouragement I'd be in despair, I think. The poor kid. Nobody would know what he'd be like without the program. But because of the program he's been mainstreamed with his own class. He's keeping up with his class in a regular DOE classroom. He is social. His only handicap now is his hearing loss in one ear and his handwriting.
>
> At birth, it was touch and go as to whether or not he would live. The pediatric-neurologist said he'd had a "trauma to his brain." He thought it would be a mild CP -- that K. wouldn't walk until age three, if at all.
>
> That's something I had to live with, adjust to and accept. I learned to cope through this program. Not just the educational side but the family side. I was devastated and it wasn't until K. took his first step at 22 months that I began to see the light at the end of the tunnel. Before that, I thought for sure I'd be pushing that child in a wheelchair for the rest of his life.

We did the things we were told to do. My husband was great. We did the exercises, the homework. The staff was excellent in all respects. It's strange to come back here and see this place. I hope it goes on forever.

I started off -- I had two of them in this program. My other son was learning disabled and he is now being mainstreamed too with a normal IQ. My little hopeless baby is right up there in the regular first grade with a normal IQ, thanks to intensive educational stimulation.

Not only staff support, but seeing other parents in the same boat as you was such a big help. Everybody was trying to help each other.

Sue (Preschool Program Teacher) is terrific with a capital "T". She should be teaching teachers. She's the one that really got my kids to read and they read really well.

It's a part of my life that's over and yet the results will never be over. Because of that start they have as good a chance as any normally born baby.

It was wonderful to have O., who is one year older than K., and K. in the same place. When the kids moved from the DOH part of the program into the DOE part, there were no hassles, no change. I couldn't believe the smoothness of shifting from one into the other. It was a treat to have K. be in the same complex from birth to six years and then mainstreamed into elementary school.

K. had lots of homework in the program and now he accepts homework as a normal thing and he really works hard at it.

I watched a videotape just this past spring of K. crawling on the floor. When you look back and see how bad off he was then and how good he is now, you know this is a great program.

Case Study:

Child A.

A. is the seventh child of part Hawaiian parents and was born at Kona Hospital on the island of Hawaii. She was seven months in gestation with birth weight 4 pounds and 14 ounces, limp upon delivery, requiring rescusitation, intubation and external cardiac massage. Cyanotic at six hours, she required oxygen and was airvacced to Kapiolani-Children's Hospital on the island of Oahu which is the only Regional Level III Perinatal Center. She required 28 days of hospitalization. Diagnosed as cerebral palsied secondary to post anoxic encephalopathy, A.'s prognosis was regarded by her physician as poor.

At age six weeks she was enrolled in the Kona Child Development Program where she received the limited services that were available in the early months of the original Department of Health program. She continued in the program to age three. By this time, the program was in its first year of collaborative effort. A. was certified by the Department of Education as an orthopedically handicapped child and she continued on into the three year old group where she received extensive educational and therapeutic treatment for five years. Her daily programming included ongoing assessments, educational and developmental activities, speech therapy, physical therapy, and occupational therapy; she participated in the school lunch program and received homemaker services and transportation provided. A. is now in her second year of regular public school where she is enrolled in a total communication program for her speech difficulties which continue because of depressed essential vocal reflexes.

A.'s mother, Mrs. L., describes her experiences with A. and the Kona Child Development Program as follows:

> When A. was born, my mother gave her a Hawaiian name, Kauiokalaniuahoeamai, which means "the beauty of heaven has arrived." The doctors told me at three months they were not doing me a favor by saving A.'s life, that she would be a vegetable. They thought they were setting a burden on my shoulders. She had to be suctioned and tube fed. My husband would hold the tube while I poured the formula in.
>
> I had ten kids in my house, eight of my own and two that were my relative's children. This was too much for me to handle with the new baby and all her problems. I was beginning to feel desperate. One day I saw the health nurse in the grocery store and I told her how I felt. She made an appointment and came to see me. She saw how I was confined to the house for 24 hours a day, just shut in, and she told me about this program -- the Kona Child Development Program.
>
> That was when I met Claire (Department of Health Occupational Therapist/Coordinator), and started A. in the program. At first it was only one hour every Friday, but oh, the relief! I looked forward to that hour all week long. Then it worked up to two hours, then to twice a week.
>
> The program taught A. everything she knows. They taught her to feed herself, they toilet trained her, they taught her grooming and hygiene. I learned, too. I don't know how I did it with A.'s problems and all those kids. If it wasn't for Claire's program I probably would have given her up.
>
> They started taking her finally five days a week. By then the program had moved from Claire's house up to Kona Hospital. The first six months of A.'s life she had to go to Honolulu for all those doctors to look at her every month. The homemaker came in and helped out. She made the beds and cooked the meals and just sort of kept everything together. The homemaker was wonderful. I don't know how people with handicapped children can survive without this program.
>
> Because of this program I know better what to expect of A. It's been so much easier for me because the program has helped me to discipline and train her. I just have so much aloha for this program.

CHAPTER FOUR

LOOKING BACK

The recognition afforded the Kona Child Development Program by the Frank Porter Graham Child Development Center, University of North Carolina at Chapel Hill, reinforced the philosophy and concepts of the program. The collaborative approach facilitated a continuum of health and educational services for the child and family, therby minimizing unnecessary stress and maximizing the growth and development of all those involved--child, family, and professionals alike.

In retrospect, there are a number of factors which influenced the method of service delivery. First and foremost are the issues dealing with personnel. Despite the union contracts with the Department of Education personnel which allow "bumping" (position shifts favoring those with longevity status), the flexibility and willingness by the personnel of the Department of Health to work cooperatively have overcome what may have been a deterring factor--staff instability. The commitment and flexibility of the staff in servicing the children and families helped keep the program operational; staff was willing to invest time and energy in training, sharing, and cooperating. The stability of the core staff, especially the occupational therapist/coordinator of the infant program and the preschool special education teacher, facilitated the bridging of the medical and educational models and staffs. The administration of Konawaena School provided for an

open climate for both Departments of Health and Education to work together; it is critical that such cooperation is available from the principal administrator before any collaborative project is embarked upon.

The rural nature of the Kona area and the sparsity of available resources required that creative efforts be made to provide services for children with special needs. By utilizing already existing services within the Departments of Health and Education and a nominal amount of additional resources ($40,000 per year), this cooperative and coordinated effort was possible. Duplication of services has been minimized and the community benefited from this collaborative effort.

CHAPTER FIVE

LOOKING AHEAD

Kona remains an area of rapid growth and development with projected increases in commercial and population growth in the near future. The need for a program that provides the full range of comprehensive services to infants and preschool-aged handicapped children in the North and South Kona areas is likewise anticipated to increase. Resources now include several pediatricians and therapists in the community as well as preschools whose personnel have been trained to identify and work with youngsters with special needs. There remains limited resources for respite care, transportation services, and sophisticated medical care (e.g., tertiary level care).

The national and local recognition gained by the Kona Child Development Program has resulted in support for services by the community--parents, professionals, and legislators--as well as provide impetus for development of needed resources. The Kona Child Development Program will continue as a collaborative and cooperative effort funded by state funds for the fiscal year 1984-1985.

With the success of the Kona Project, preliminary steps have been taken by the Departments of Health and Education for replication of the program in Waimea, a rural and isolated area of northeast Kona where resources for handicapped children between birth and age three with the Department of Education providing services to those eligible children three and above. Through the Jobs Bill Project, the Kona Child Development Program has placed an outreach aide in the Waimea area to identify needs as well as to identify

and begin providing follow-up services for those developmentally delayed/disabled children. Perhaps in the future, the concepts of the Kona Project can be replicated in other areas of the State of Hawaii and elsewhere.

SUMMARY

The Kona Child Development Program was selected by the Frank Porter Graham Child Development Center, University of North Carolina at Chapel Hill, as an exemplary program of national significance. Cited as outstanding features of this model program were the following:

1. successful interagency cooperation and collaboration;
2. effective integration of health, educational and related services;
3. attention to the "total child" concept and dedication to meeting the needs of a given child;
4. benefits to the child, parents, and general community--including its initiative in early identification and treatment within a continuum of services;
5. cost effectiveness

Success of the program has provided the impetus for replication elsewhere on the island.

APPENDIX

National Review Project Report

VIGNETTE:

KONA CHILD DEVELOPMENT PROGRAM

Anne M. Hocutt*

The Kona Child Development Program, located in Kealakekua, Hawaii, is a model demonstration program having a cognitive-developmental theoretical base. The primary goal of this program is to provide an integrated continuum of health and educational services; the intent is to demonstrate a service model which may be used as a basis for requesting state support for these services in the rural areas of Hawaii. Objectives are to mainstream specific numbers of children in certain classrooms/schools/programs and to enable the children served to progress in accordance with their individualized programs. Exemplary features are interagency collaboration at the state level and the monitoring of the childrens' progress through data collection and evaluation.

The sponsors of the program, which was begun in 1978 with Title V, Title XX, and state funds, are the Hawaii Department of Education and the Hawaii Department of Health. The program is center-based and serves West Hawaii County, which is rural. Thirty-two children are served directly and one indirectly; their ages run from 0 to 6, and they suffer from mental retardation (10), cerebral palsy (2), speech impairment (1), blindness/visual impairment (4), orthopedic handicap (2), emotional disturbance (1), learning disability (6), language/developmental delay (2), and multiple handicaps (5).

*Bristol, M. M. & Bartel, J. M., A Compendium of Exemplary, Comprehensive Programs for Young Developmentally Disabled Children, (prepared for the National Review off Child Development Services Project), Chapel Hill: Frank Porter Graham Child Development Center, University of North Carolina, 1981.

The overwhelming majority (80%) of the families from which the children come have incomes ranging from $10,000 to $14,999; the remainder of the families have relatively low income levels ($5,000 - $9,999 -- 15%) or higher levels ($15,000 - $19,999 -- 5%). Fifty percent of the children are part Hawaiian, 25% are Oriental and 25% are Caucasian. There are no restrictions on eligibility, although the six-year-old children are served because there is no other appropriate placement for them.

The program receives its overall direction and coordination from a program coordinator, a Department of Health employee. General staff supervision responsibilities are shared by this coordinator and the Konawaena School principal, who is affiliated with the Department of Education. Supervisory controls and decisions are cooperative interagency actions. In addition to the coordinator, (who is also an occupational therapist) the staff consists of two full-time special education teachers, four part-time educational assistants, a full-time homemaker, a full-time medical social worker, a part-time para-medical assistant, a part-time physical therapist, and a part-time speech/hearing therapist. A pediatric consultant and a psychological consultant are available on an "as-needed" basis.

Child find activities are conducted through a public service announcement column which appears three times a week in a local newspaper; a pre-school screening project; an Operation Search conducted by the Department of Education; and general awareness of social service professionals, pediatricians, public health nurses and school health nurses of the program's services.

Assessment services are provided under the auspices of either the Department of Health or the Department of Education, or on a fee-for-service

basis; such assessments may be done by professionals in special education, occupational therapy, physical therapy, speech therapy, social work services, homemaker services, psychological consultation, developmental testing, and a Department of Health diagnostic team.

Transportation for most of the children are provided by the families; the only exception to this is that 3- to 6-year olds who have been DOE certified received transportation from this Department; the transportation is door-to-door except when roads are inaccessible (then it is to an access highway).

The program staff is considering the development of a checklist for follow-along information; at present, procedures in this area depend partly upon the program to which the child is discharged and partly upon staff efforts.

A typical individual program would take place six hours a day, five days a week. During that time, a child (depending upon his handicap and length of time in the program) would receive psychological and pediatric examinations, educational/developmental services, physical therapy, speech therapy; the parents might be involved in IEP development, home activities, school visits and receive quarterly evaluations, social worker services, homemaker services and training sessions. Services which a child might receive because of linkages between this program and other agencies might include clinic services (cardiac clinic, orthopedic clinic, etc.), regular preschool services, and a supplemental food program. The child would leave the program at such time as his developmental and educational progress would enable him to leave, or when he/she reached the age of 6. Contact would be made with the teacher of the new classroom and would be made easier since the Child Development Program is part of the regular elementary school in the community.

If a child is aged 0-2, the primary services consist of early identification, assessment and intervention designed to enable him/her to move smoothly into the preschool group. The children aged 3-5 are divided into small groups for teacher-directed learning, which enables them to achieve many stated educational and developmental goals. The six-year-olds are usually mainstreamed (successfully) into the resource room of the Konawaena Elementary School.

All children entering the program are evaluated and, as stated above, quarterly program evaluations are also done. The basic instrument used is the LAP (Learning Accomplishment Profile); additional evaluations are done with the Southern California Sensory Integration Tests, the Brigance-Diagnostic Inventory of Early Development, the Frostig Developmental Test of Visual Perception, the Illinois Test of Psycholinguistic Abilities, an Upper and Lower Extremity Motor Development Test (developed by the Department of Health). Evaluation data have been reviewed by Department of Education Board Members, a Title XX Evaluation team, a District Curriculum Specialist, and Federal teams.

In-service training of staff is accomplished through informal sessions once a week with staff who work with infants, once a week with teacher and educational assistants, and once a month or every other month with a pediatrician and psychologist.

The primary mechanisms for service coordination have been interagency and transdisciplinary cooperation and multiple funding, allowing resources to be integrated so that an effective continuum of developmental and educational services may be offered. This approach has been used in order to serve the "total child", meaning that all unique needs of the child may be met.

Purchase of service has been used by the program to provide pediatric and psychological evaluations; written agreements with the sponsoring state agencies have been used to provide assistance for teachers of visually impaired children, dental clinic services, orthopedic clinic services, psychiatric services, and social worker services. Although no barriers to the coordination of services have been identified by this program's staff, service gaps are still evident in the areas of appropriate placment for some of the older children (6 years), limited options for children not certified as TMR but not ready for kindergarten (who may end up in a TMR class), transportation, respite services and recreational services. However, the primary benefits of the program have been comprehensive services, continual updating of program objectives, awnd ,complete diagnostic evaluations for the children; sessions in parenting skills, learning how to meet a child's unique needs, and homework activities for parents; agency collaboration, cost-effective service provision, and services to handicapped preschool-aged children for the community.

It costs $924 per child to the Department of Health; the Department of Education's contribution is difficult to calculate because it consists of part-time mainstreaming of children into resource classrooms and use of staff time of the Department's diagnostic team. The Department of Health figures include direct services, staff salaries and fringe benefits, mileage, travel, supplies, equipment and fee for service. There is no cost to parents.

Funding for the program from the Department of Health comes from Title V -- Maternal and Child Health (42%); Title XX -- Social Security (13%); and from state funds (45%). Funding from the Department of Education goes for salaries (50% from P.L. 94-142 and 50% from state funds) and for supplies (80% from P.L. 94-142 and 20% from state funds).

Future directions of this program are clearly directed toward recognized gaps in services: if expanded resources were available, staff would provide weekend and/or after-school recreation, respite services, additional transportation services, and an outreach program. In addition, program staff would promote increased interaction between handicapped children and their normal peers through activity overlaps with regular preschool programs.

In summary, the Kona Child Development Program is considered an exemplary service program because of clear evidence of successful interagency cooperation and collaboration; because of the consequent integration of health, educational and related services; because of its attention to the "total child" concept and dedication to meeting the unique needs of a given child; because its benefits include not only the child, but also the parents and the general community; because of evidence of its cost-effectiveness; and because of careful documentation of child progress.*

*Ten Criteria For An Ideal, Comprehensive Service Program for Young Developmentally Disabled Children used by the National Review Project on the Integration of Human Services for Young Developmentally Disabled Children:

1) Child find: A coordinated mechanism for identifying potential clients, assessing needs, and locating appropriate services to meet client needs. This would include a mechanism for an initial screening or brief assessment that would identify children in need of further evaluation and, possibly, intervention.

2) Multi- or trans-disciplinary diagnosis and assessment: A coordinated evaluation by a team of specialists from a variety of fields who assess the status and function of the child in all major developmental areas. Such an assessment team might include a psychologist, a physician, an educator, a social worker, a speech therapist, a physical therapist and other professionals with training and experience relevant to both the child's and family's needs.

3) Individual treatment or habilitation plan: A plan written with parental input and consent which usually specifies strengths and weaknesses of the child, present level of functioning, specific long and short range objectives for programming, and provides for periodic re-evaluation and revision. The plan may be called an Individual Treatment, Habilitation, Education, Service, or Program Plan depending on the sponsoring agency.

4) Comprehensive services: A full range of programmatic services designed to meet the individual client's needs provided through coordination or integration of services among multiple service providers.

5) Consumer involvement: Opportunities for active involvement of parents in all phases of program operation including both the design and evaluation of programs for their individual child and significant input into overall program design and evaluation.

6) Follow-along: A formal mechanism to insure that the child actually receives needed additional services provided outside the scope of an individual program. These services may be provided either concurrently with ongoing treatment or through referral or transfer to another agency at the time of termination of primary service responsibility.

7) Evidence of program effectiveness: Some systematic evidence in addition to monitoring of individual child progress which shows that the overall program is effective in facilitating the progress of groups of children.

8) Staff training: Evidence that program staff have appropriate and sufficient training and experience to meet client needs and that continuing inservice training is provided to maintain and upgrade staff knowledge and skills.

9) Theoretical adequacy and consistency: Evidence that the treatment program represents a consistent programmatic approach based on the best available knowledge regarding the prevention, amelioration, or rehabilitation of processes which cause or complicate developmental disabilities in young children.

10) Case management system: The assignment of a specific person responsible for assuring, documenting, and evaluating continuity of care for an individual developmentally disabled person throughout all phases of treatment both within a given agency and across agencies. This person may be located either within or outside the service providing agency or agencies. The case management system should allow for review and redirection throughout the life span of the client as well as provide standby availability to assist the individual with unanticipated problems.